The Need for More Effective Patient- and Family-centred Care

Report on the patient experience component of the Saskatchewan Patient First Review

Prepared by KPMG

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Patient First

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1. Summary Report Overview

The enclosed report provides a summary of the research, findings and recommendations captured from the conduct of the Patient Experience component of the Patient First Review. The Government of Saskatchewan commissioned KPMG to manage the patient experience research. This report reflects a summarized version of the detailed report, which provides the research team's complete findings and recommendations.

The detailed report can be found online at www.health.gov.sk.ca/patient-first-review .

2. Introduction

"Is this the best we can do?" That is the core question driving the Patient First Review. Canadian governments have asked this question before, from the perspective of clinical outcomes or economic value for money, but never from the perspective of the patient.

In fact, the Patient First Review has split that basic question into two:

- Can we do better for patients?
- Can we get better value for the dollar in the health administrative services to free up more resources for health delivery?

The Patient Experience component of the Patient First Review looked to answer the first of these two fundamental questions by seeking the input of patients, health care providers and stakeholders on what the actual patient journey is like in Saskatchewan and what can be done to make it better.

Participation from patients, providers and stakeholders in the Patient Experience component of the Review was enthusiastic. Over 4,000 responses were collected across the four phases of the research. Just over 2,500 people participated in the initial patient experience consultation (Phase 1). Just over 500 health care providers and ancillary staff participated in the various provider consultations (Phase 2). 82 stakeholder representatives participated in the three stakeholder sessions and 168 workbooks were completed in the stakeholder consultation phase of the research (Phase 3). Finally, 1,076 Saskatchewan residents completed a random telephone survey.

The extensive process to collect and respond to the patient perspective has forced the Patient First Review team to challenge our assumptions and think outside the box. The

patient voice has left the Review with some unique conclusions that set the Patient First Review apart from previous studies.

Placing patients first adds important dimensions to how we judge the success or failure of the health care system.

Patients received both the first and last word in this Review. Patients spoke first through the Phase 1 patient experience consultations and they wrapped up the consultations in the random telephone survey. Their personal stories brought into focus the human price too many patients are paying because of problems in the system today. By putting patients first, we heard the health care system judged not in terms of productivity or efficiency or even clinical outcomes, but in terms of pain, suffering, worry and fear.

> *"I've had a couple of my surgeries cancelled due to NO beds available after my surgery. I would have had to stay for 10 days and there were no beds. So I had to wait for 6 more months. Not pleasant with my illness. I was in constant pain and lost over 70 pounds. Then 2 times I sat in my hospital gown, fasting since the night before and it wasn't until 5:30 pm that I was told it was cancelled because an emergency surgery was being performed and the other time the emergency room was busy, so there was no bed for me. That made me mad!"*
> *(Patient)*

Success was not measured in dollars per case or length of stay, but through relief, joy, peace of mind and confidence. Too often health care is considered only in terms of its monetary costs, but this report is founded on the human price and benefits.

> *"A couple of nurses went out of their way to help, and REALLY LISTEN to our concerns, and answer our questions. I actually made a list of my questions at one point, and was able to persuade the nurse to bring the chart into the room and take all the time needed to answer each question. After she left, the other patient in the room even remarked about how good that nurse was, to spend the time to actually answer all those questions and explain things!"*
> *(Patient)*

Navigation and coordination failures are key drivers of fear and anxiety

One key finding related to this new perspective is the importance of navigation and coordination in the health care system. A journey through the system can be a terrifying experience. The terror most often comes not from what any provider does or says, but from uncertainty and fear of the unknown.

> *"If you feel like you can't breathe it's the scariest thing in the world. When I arrived at the hospital there wasn't a seat to be had. I asked the lady there - I'm not sure if she was a nurse or what she was - if I could go to another hospital. She said it wouldn't be long but she didn't tell me how long it would be. She gave me some forms to fill out but I told her I couldn't do them right away because I thought I was having a*

heart attack. I had to sit on the floor because I didn't have strength. I just curled up on the floor. They finally took me in after about forty minutes or so of me just sitting there, slumped on the floor, feeling like I couldn't breathe. It was so frightening. "
(Patient)

Again and again stories about patients' negative experiences involved their inability to navigate particular parts of their health journey or in the failure of the system to provide the patient with one individual who works regularly with the patient and keeps track of the patient's health challenges and the system's various responses. The Patient First Review Province-wide telephone survey shows that almost half of Saskatchewan residents are worried that the health care system is so complex that they won't be able to find the help they need. Those people who are not confident in their ability to find the care they need are much more likely to give the health care they receive a low grade. In some cases those who are not confident are twice as likely to give a negative score as those who are confident in their ability to navigate the system.

"It can be very difficult when you are sick to take control of all of your appointments and what you need to do, especially if you are not used to it. You need someone to help you. You basically have to be a doctor to navigate your way through the health care system here in Saskatchewan!"
(Patient)

"There is no follow up, there are so many people who are alone and have nobody, and there are so many people who need support, they just need somebody to check on them."
(Patient)

Contrast those experiences with the ones below which shows for some people the ideal health care system is right here and now in Saskatchewan.

"I really like that my family doctor is not only my doctor, but also my kids' doctor. It means that I only have to go see one. If I have a question about myself in the middle of my kids' appointments, I can ask that question. And it's great because they know who you are; my doctor always remembers us and asks different things about my kids even though they aren't always there. It just shows that she really cares, and that is nice."
(Patient)

"I would credit my cancer care to my family doctor. She had a good chain of communication and contacts. After finding the lump we moved very quickly through the health care system. I felt that everything was under control."
(Patient)

Unfortunately, for too many people, the story of one regular doctor who knows and cares for your whole family and navigates the system for you is still a dream. Yet many positive experiences highlighted the role of a health provider, often a family doctor, who went out of

his or her way to make connections and undertake follow-ups to ensure that patients received the care they needed, when they needed it. We recognize that with primary care reform in progress, the key primary care navigator may not be a doctor, but that is the reality for the average Saskatchewan patient today.

The critical importance of primary care to managing health care transitions is highlighted in the Patient First Province-wide telephone survey. More than half the problems with transitions from one part of the system to another start when patients are leaving primary care. Generally they are transferring to a specialist doctor or for diagnostic testing. Organizations such as hospitals with discharging planning systems or 'most responsible' physicians can't help solve these problems because they are not part of the process in many cases.

This question of navigation and co-ordination is already on the health system's radar screen when it talks about electronic health records, primary care reform, discharge planning or cancer patient advocates. But these initiatives take on a whole new level of urgency when we consider the price patients and their families pay everyday in fear alone.

We will not see a permanent change in the patient experience if we keep running the system the same way we always have.

This is hardly a new insight. After all Albert Einstein said "Insanity is doing the same thing over and over and expecting different results" as well as "We can't solve problems by using the same kind of thinking we used when we created them". The patient story is of paramount importance to health care planning. The metrics that are currently used to plan and manage the system include clinical outcomes, budgets, and occasionally, surveys. But pain and suffering, relief and peace of mind don't lend themselves to quarterly updates and annual plans.

We not only have to change what we are doing, we have to change how we are doing it. What is required is a fundamental change in culture and processes. We won't get one without the other.

The transformation will not be complete until providers talk about patients as people they work <u>with</u>, not people they work <u>on</u>.

Collaboration is a key principle that Saskatchewan's health leadership appears to have embraced, but it remains to be fully implemented. The traditional health care administrative model is a top down, leadership driven approach that drives a one size fits all delivery system.

"My mother said to me after seeing her doctor, "I don't think he hears me when I talk." She doesn't feel looked after."
(Patient)

"Doctors just don't listen to you. The difference between God and the doctors in this Province is that God doesn't pretend to be a doctor."
(Patient)

That model will not allow the system to deliver individualized care and is de-motivating for providers as well.

Saskatchewan is already moving towards a more collaborative approach both in terms of planning for a cultural shift that focuses on value to the customer and eliminating waste by applying approaches such as Lean, and in health delivery in initiatives such as primary care reform. However, while it is good that the system is moving towards more collaborative models between policy makers, managers and providers, we can't stop there. The system will not become more patient-centred unless the process of planning and managing involves patients.

"Up until the last 18 months of my life I have always been an extremely healthy person and I have rarely had to access the health system. I always regarded the health care system with pride and trust and good faith. I felt assured and assumed that the care, should I ever need it, would be nothing less than the best. However, my past experience over the last 18 months or so has proven to me how naive I was. Not only has my experience opened my eyes to the realities of our system, but it has caused me to be extremely apprehensive about accessing the health care system and any future care I might receive. I realize there are no easy answers to the problems that face our health care however that is no excuse for what exists now. Over the past 18 months I have felt extremely frustrated. I was a patient but I did not have a voice. Things were happening to me that I could not control and I felt that I had no active part in that process neither was it encouraged or welcomed. I was very happy when I heard about this survey because it made me feel like I would finally have a chance to have a "voice" that would allow me to express my concerns I have had regarding my experience. My hope is that this survey will result in some positive changes for our health care system. It is needed."
(Patient)

This patient is not unique. Consumerism is growing in health care. Consumerism is a trend of changing patient-provider relations where patients expect to be treated with the same level of care and deference that marks the best consumer marketplace experiences. Patients who are high in consumerism expect timely care and responsive answers to their questions. Patients who are low in consumerism defer to their main caregiver's advice; those high in consumerism often seek alternative information and advice. In this survey, we have included one statement that covers the deference dimension of consumerism, "I like to do my own research before I take my doctor's advice". More than half (56%) of all patients agree with the statement. While some patients remain deferential, a majority expect to be major decision-makers in their own care and 1-in-5 passionately hold that belief. Not surprising given stories such as the one above, people who hold consumerist views are less satisfied with the current system than those who are more deferential. However, it is important to note that a high level of consumerism is a less powerful driver of system approval than low levels of confidence in system navigation.

In the evaluation of other systems moving towards a patient-centred approach, it is clear that the active engagement of patients in planning and delivery is key to the transformation. Structurally, that means the engagement of patients on a routine basis on any planning exercise within the sector as well as the development of new accountability tools. Culturally, it means that providers need to look at patients as partners in their care plan and in decision-making.

Every dollar spent on administrative overheads must be justified against its potential use in buying improvements in patient services.

Participants in the review generated a number of ideas for improvements that involve better use of existing resources, but there is no question that significant improvement in service will require additional resources. The first place to look for those needed resources should be the money already committed to health care.

On the clinical side, that process has begun with moves toward a cultural shift known as Lean. That type of review has enjoyed wide support among provider groups and is building momentum in its application within the health care system.

"I am a big supporter of Lean. You have to eliminate inefficiencies and waste – everything needs to bring value for the patient."
(Health care provider)

We need to bring the same approach to administration. Let us be clear, we recognize that administrative functions such as supply chain management, human resources, information technology and general administration are critical supports to front line workers. We all need to appreciate the contributions made by people in those functions. But like every aspect of the system, we need to challenge past practice and ask ourselves if we can't do better, if there is not some way we can get more value out of our existing budget and free up funding to buy change.

3. What Are Patients Looking For?

What do we mean when we talk about change for the better?

In the first phase of the Patient Experience component of the Review, we explored how members of the public experience the health care system, through an online and mail-back workbook (2,247 participants) that was open to everyone in Saskatchewan. The public also participated in the process through randomly selected qualitative research conducted in one-on-one, small group or large group consultations, as appropriate. The experiences gathered from this process were checked and confirmed in the second stage of research with providers where 413 providers shared their views through an online and mail back workbook, and 94 providers participated in a series of 10 focus groups across the Province.

Both patients and providers were given the opportunity to provide input on three key research questions:

1. What has been your experience in the Saskatchewan health care system?
2. What are the key factors that you feel drive that experience?
3. What ideas would you suggest to ensure good experiences are sustained and bad experiences are avoided?

Not only did the negative patient experience stories show what needs to be improved, the positive stories helped us understand the system that patients want. There is one basic consideration that is the minimum commitment patients require from the system – error free medicine. While patients understand health care is delivered by people and people make mistakes, nothing will more quickly raise the public's ire than a story of delayed or mistaken diagnosis. We will return to this theme shortly. But what does the system need to do to rise above the acceptable?

The patient-centred system Saskatchewan patients want has five key characteristics:

1. Fast access to needed services
2. Effective case management and coordination
3. Good two-way communications
4. Providers who show they care
5. Recognition of the unique needs of underserved populations and regions

In the following pages, we illustrate those priorities both by looking at what is missing from negative experiences as well as looking at what is driving the positive experiences. To be clear, the future we want can already be seen in the many examples of positive experiences patients shared. But the areas for improvement can be seen even more starkly in the negative experiences we show beside each positive experience.

Lack of access or delayed access to needed services versus fast access to needed services

A patient-centred system will provide patients with fast access to the services they need from the start of their journey to the end. Patients with negative experiences often report limited access to a variety of services starting with family doctors or alternative primary care services (including home care), emergency or urgent care and access to specialized care including access to specialists, diagnostics, long term care, mental health services and addiction services. In addition, when services are available, patients frequently report extensive wait times to access the available services. These delays can be measured in hours for treatment in ER, in months for diagnostic services, and in years for some surgeries. On average 3-in-10 recent patient experiences generate poor or very poor approval ratings in the Patient First Province-wide telephone survey. Mentions of reduced waiting times or staffing and capacity increases dominate suggestions for improvements. Access is the dominant concern of patients.

FAST ACCESS TO NEEDED SERVICES	
Positive	**Negative**
"I knew the doctor and he was able to get me in for my knee operation. The nurses were excellent, the operation was not an overnight stay and it was able to be done within an hour of my home. I was able to get in for the operation in a reasonable length of time - about six months - and best of all the operation greatly reduced my pain."	*"I am on a waiting list for a knee replacement, and have phoned the Health Region, and talked with my local doctors, but cannot get a consistent date of when my surgery will be. I live alone on a farm, and it is limiting my ability to get around. I tell my doctor this, but it doesn't help as he blames the Health Region. When I phone the Health Region, the lady answering the phone blames the doctors and nurses. It is confusing, and they just shift the blame rather than getting to the root of the problem and letting people know what is actually going on. I have said my complaint to the Patient Advocate, but this also has not helped. I am frustrated, and would have had new knees by now if I had just gone to Alberta and paid for it."*
"I went to emergency on a Friday with severe pain, saw a surgeon very quickly, had a CT scan, was diagnosed with ovarian cancer, was admitted by midnight, saw a specialist on Monday, surgery on Wednesday - very speedy service."	*"My wife has cervical cancer. It was diagnosed in 2005. The family Doctor she had before the cancer was found did not find the problem. The wife went back when she was in a lot of pain. The Doctor put her on pills for pain. He told her to come back when done. The pain in her legs and back were getting worse. Then the Doctor told her it was her back and she needed orthopedic shoes and said she was going to send her to a Back Specialist, which took 5 months to get in and see. This Doctor, when she did get in said that there was nothing wrong with her back. Back to her family Doctor, more pills. Then one night pain was so bad she went to the Hospital. She got to see an Oncologist. Did some tests and was sent home. Went to the Oncologist office and was told about the cancer. But was told if it was found out a few months earlier it could have been taken care of."*
"Again the system has worked for me, I have a wonderful doctor and when I was needing to seek help from a psychiatrist, I was able to see an excellent practitioner and I have benefited immensely from this. The response was timely and I have since recovered."	*"I have been extremely disappointed with the Mental Health system in Saskatchewan. We moved here from Ontario where we had an excellent family doctor and a wonderful Cognitive Psychologist to provide excellent medical care. When we asked one of our first family doctors here about a cognitive psychologist, he replied "A what?". This does not inspire confidence. The family doctor that we are currently with seems to be willing to at least put a little effort into the process and prescribed an additional anti-depressant and then referred my husband to a psychiatrist. But when we received the phone call to set up an appointment, we were told it was a nine-month wait list."*

Feeling lost in the system, or poor case management, versus being connected to the system

A patient-centred system will give patients a clear sense of confidence as to where they are in their health journey and who is looking out for them. Many patients who report negative experiences encounter poor transitions across health delivery silos or experience health conditions that require care from multiple providers where information and/or treatments are poorly coordinated. As a result, they can receive confusing or conflicting directives and often there appears to be no one in charge or aware of the patient's total health experience. The Patient First Province-wide telephone survey shows almost half of the Province doubts their ability to find the health care they need. Those people judge the system far more harshly than those who are confident. The results also show 1-in-5 patient experiences generate poor or very poor ratings for transitions between service silos while 1-in-8 cases generates poor or very poor ratings in staff communications of next steps. Better case management by all its names is a critical goal every way we look at it.

EFFECTIVE CASE MANAGEMENT AND COORDINATION	
Positive	**Negative**
"I have some problems with my knees and my doctor was able to get me into a trial at the Kinesiology centre that worked with people to evaluate conditions prior to having to see a specialist. This saved the time of the specialist as well as was able to resolve my problem quicker."	*"I have lower back problems so I asked my doctor what my options are beyond pain killers. My Doctor wasn't very helpful and just said there is nothing she can really do to stop the deterioration before surgery. And we don't know if I'll need that. I just wanted a second opinion but she was so eager to just prescribe pain medications – and she refused to listen. I'm reluctant to take the pain medication because they don't agree with me and they are very addictive. I just want to know if there are specific back doctors that I can go to."*
"My mother has Alzheimer's and the health care workers are generally kind and patient. I had an amazing Home care co-coordinator - I think it's SWADD - who advocated so well on behalf of me and my mother - and father when he was alive."	*"I have two boys with autism and there is no coordination of autism services in this province. That is a key factor in making our experience with the health care system negative. Lack of case coordination forces parents to become case managers for their children. It forces us, on top of all the care required for our children, to read and learn as much as we can about autism and the many, many facets of the disorder. We run the risk of being influenced by quacks with unscientific remedies. We need case managers who have an expertise and background in autism to help us understand what kinds of services may help with the behaviours or physical problems. Our children have mobility issues, sensory issues, sleep issues, communication issues, daily living skill issues, nutrition issues and more. We live with our children 24 hours a day and when they are struggling, we need support and education to learn how to possibly prevent the behaviours, we need help to keep our families together, we need to learn how to communicate with our children, we need experts to suggest ways to manage the problems that we face every day."*
"The care was immediate and consistent throughout my husband's emergency. After his surgery, the follow-up was excellent. The information provided by the emergency room nurses and clerks was thorough and the compassion was genuine."	*"I was ill-prepared for my surgery, due to my physician not informing me of the overnight stay and the recuperation period (4-6 weeks off from work and a 2 ½ week back to work program implemented by my employer, to accommodate me, on short notice). Post-surgery I was catheterized without being informed prior to surgery and upon awaking from anesthetic was startled to find the tube that I had tugged almost fully out and had to be put back in. I have been told by many friends, family and co-workers that they were not fully informed on the details of surgery and recouping time."*
"There is a diabetes collaborative in place in my community. Access to lab services for A1C testing is quick. We have nurse educators to assist in care if needed."	*"My community has a large diabetic population and they do not have a dialysis service here so patients have to travel to Saskatoon to receive treatment. Some cannot afford the extra cost of travel and food."*

Poor communications and dismissive attitudes versus good two-way physician-patient communications

A patient-centred system will ensure patients not only have their questions answered quickly and thoroughly, but will take the initiative to provide the information a patient may need even if they are not yet aware of that need. Many current negative experiences involve patients who can not get their questions answered, receive answers that are in complex or in otherwise hard to understand language, receive inconsistent answers or experience rude or abusive behaviour. Language barriers are also a challenge, both with patients who are not fluent in English as well as with providers for whom English is a second language. The Patient First Province-wide telephone survey found 3-in-10 patients have experienced unacceptable behaviour with First Nations and Métis experience at 45%. Improved patient-provider interactions are the second most common open-ended suggestion for improvement in the survey. This is clearly a major priority for patients.

GOOD TWO-WAY COMMUNICATION	
Positive	**Negative**
"My experience with a specialist was positive. I had had to do a lot of my own education about managing after my incident because it was a month from the incident (which occurred out-of-province) to my appointment with the specialist. When I did see him, I was able to discuss my concerns about a number of aspects of managing my condition, discuss my goals, and receive the kind of specific guidelines I needed to return to normal. He listened and respected what I had to say. He gave me his undivided attention and the time to learn enough about me to provide useful advice. Another positive was working with a nurse practitioner. Again, she listened and agreed to work with me to implement the plan I had discussed with the specialist. The other positive encounter has been with pharmacists. Thanks to them, I was alerted to potential dangers with my medications, side-effects which need to be reported, and lab work which is very important to do as long as I take a certain one. Their information was invaluable, as I did need to get medications changed."	*"I was diagnosed with a rare form of cancer. Passed around to several doctors, surgeons and oncologists. Then referred out of province. I felt like no one was responsible for my care. Follow up would be recommended but no one knew who was in charge of my care so it was never done. I found this out by getting a copy of my chart to ensure that I receive the appropriate follow up. I feel like the only one looking out for my care is me, however the health system is not "user friendly" for patients. For example, obtaining copies of my notes or radiology films usually involved several visits, signatures and sometimes requires me to get other health care people to request on my behalf. One department's release of information policies would be different than the rest. In my situation, I was going through the system on an urgent basis and did not have the time, energy or knowledge to be looking after my own care. There was also a lack of communication between facilities, departments, specialist, hospitals that made my care not very consistent."*
"[My doctor] is patient, understanding and very caring. He doesn't rush you through your appointment and helps us understand the process in which we are going and will be going. He is very thorough."	*"I always feel rushed through when I go see my family doctor. I am only allowed one problem per appointment and it makes me so frustrated because some things might be related. Doctors are too overbooked, they see too many patients. But if the alternative is not seeing me at all, I guess I'll take the partial care."*

(Table continued on next page)

GOOD TWO-WAY COMMUNICATION	
Positive	**Negative**
"We have been involved with home care and the geriatric assessment unit at the hospital for the last six months. There has not been a single negative situation during that time. My mother gets two baths per week. I have been present a couple of times when the home care Aides were working with my mother and they were fantastic. One lady was incredible, she helped us at every step and she was a wealth of information. Another home care Nurse was the same. With the general condition of the health care system in Saskatchewan, our experience with home care was very good. Thank You!"	*"When mother was in her final stages, home care came in to help with blood pressure checks. I appreciated their coming in, but my expectations were that they would know more than me about what's wrong and when we should go to the hospital and that sort of thing. But this person just did blood pressure, that's it. I didn't get a clue from the person to relieve questions and anxiety."*
"I was diagnosed with prostate cancer in June of 2008. I was referred to an excellent urologist who consulted with both myself and my wife and gave us very straight talk on my options - he also provided several books which confirmed what he told us. I opted for surgery and was put on a waiting list - I was called for surgery on Oct 1/08. The surgery went well, I received excellent nursing care and daily visits from my urologist. I was home after 5 - 6 days and am expecting full recovery."	*"I received notice on Dec. 4, 2008, that I am to have cataract surgery – at the end of March – a wait of 4 months. Then I received 2 letters from the Health Region OR Scheduling Office to call. I did call, and was informed the wait time would be 6-9 months. The letters state "If you have already been scheduled or have had your surgery, please disregard this letter." So here we have a scheduling office which doesn't know who is having surgery and who is not. And they tell me I have to wait 6-9 months. The doctor's office says "Disregard this nonsense. We do our own booking and scheduling, and we'll see you Mar. 31. Now, I want to know what this OR Scheduling Office is and why are we, as taxpayers, having to pay for it. Clearly, it serves no useful purpose, and seems to be working at odds with the surgeon's office. There is a difference between a 4 month wait and a 6-9 month wait. I tried to speak to the manager of this office, but he/she has never returned my call."*

Uncaring attitudes versus genuine caring attitudes

A patient-centred system will make sure that patients are treated with care and respect. All too often, negative experiences are driven by patient-provider interactions that leave patients feeling the provider doesn't care about them or is judging them and finding them wanting. Patients with an illness or injury are already experiencing tremendous fear and uncertainty. A smile and a kind word can make all the difference. In the extreme cases where discourtesy descends to rudeness or even abuse, the relationship of trust between a patient and his or her caregiver can be shattered and the resulting distrust can then impact the patient's health outcome. The vast majority of respondents to the Patient First Province-wide telephone survey agree "In general, health care workers in my community care about patients and treat them with respect" (89%). Yet despite that general belief, there are still regular incidences of specific communications breakdowns with 7% poor ratings for staff courteousness and 9% poor ratings for listening – leaving room for improvement even in this relatively strong area.

PROVIDERS WHO SHOW THEY CARE	
Positive	**Negative**
"I received immediate and compassionate care during several very difficult situations involving my reproductive health. The women who cared for me, the Dr, RN, unit clerks, even the women who worked at the information booth were very sincere, patient and calm ."	*"I was in the hospital having a pelvic exam when the obstetrician took a personal phone call while he was examining me. Here I am sitting with my legs in stirrups and his phone starts making a moo-ing sound or a rooster sound. The nurse was holding the phone up to his ear so he could chat while I was lying on the table in a compromised position."*
"I encountered many nurses, ambulance attendants, security personnel who were very compassionate in their care for me. I was paralyzed and unable to speak because of a brain tumor and my wife was beside me 24/7. She often received care and comfort from the staff in the form of warm blankets, bedside chair beds, and emotional support."	*"When you do go to the ER, it's almost like you are intruding on the nurse's time. They have their tasks they need to do, and they are always so busy doing their tasks that it's almost like a 'don't bug me, you are invading my space' attitude, which is very frustrating."*
"What was positive was the fact that the staff in the home where my mother was were understanding, updated daily on the patient's medical condition and are dedicated to making life comfortable for those in long term care."	*"My friend's son is in long-term care and it really bothers me because the way they dress him is so awful and disrespectful. They wouldn't go out on the street looking the way they dress him to look. I don't know why they don't try harder."*
"The programs at Four Directions Community Health Centre are good. It's good that you can walk in to most things like the Hepatitis C program with the nurse at the clinic. It's not judgmental and they remember you. You can also do cooking classes and things, which help if you're feeding kids and trying to stay healthy yourself."	*"I'm not sure if the nurse knew that I used to be a junkie but when she went to do the blood draw she said: 'I don't know why you need me. You know how to stick a needle in your arm.' Maybe it was supposed to be lighthearted, but nurses aren't supposed to talk like that to anyone. The sign that bothers me the most in the hospital is the one that says 'we will not tolerate any abuse – 0 tolerance'...but often when you leave, you are the ones who feels like you've been abused."*
"Our son was born with a heart defect. Our doctors were so great at looking after him. They prepared us and him. They spoke to him at his level and us at our level. It made all the difference and made us all more comfortable with what was happening."	*"I went to one specialist who kept referring to my two-year-old daughter as 'it'. When my husband corrected him, his response was "when you've been doing this for as long as I have, they are all 'it'." Last time I checked, my daughter was a human being, not an object."*

Recognizing the unique needs of under-served regions and populations

A patient-centred system will recognize the cultural and regional diversity of Saskatchewan and provide care in a manner that respects both distances and diversity. Some negative experiences, particular among First Nations and Métis, were driven or compounded by culturally inappropriate communications and outright racism. Other people living in remote and rural areas described feeling "forgotten" and heavily burdened by the need to travel great distances to access appropriate care for themselves and their families. Consistent with the findings from the discussion groups, the Patient First Province-wide telephone survey found that First Nations, Métis and residents of rural regions generally report lower satisfaction ratings than other groups, providing further support for this item.

Recognizing the Unique Needs of Underserved Populations and Regions	
Positive	**Negative**
"The Counselor was very understanding and could speak my own language which is Cree"	*"Elders have a hard time communicating with the medical staff at the facility. Elders can only speak Cree."*
"My mother-in-law had knee replacement surgery. Coming from a small northern community (she rarely leaves the community), she is not as comfortable speaking English, but everyone at the hospital was great."	*"Doctors do not speak in basic language when discussing the diagnosis with the elderly and non-educated people in my community. As a result, some do not understand their condition when leaving the hospital."*
"The Hospital has a spiritual room where I was allowed to participate in my cultural practices. I was pleased with my experience because the hospital asked which tribe I belonged to in an effort to identify the right Elder Tribal leader."	*"Now relating to the Cardiac Rehab program, I notice that it appears to be for white people only. No Aboriginal people there except myself. When I asked the staff about this, they said yes, the aboriginal people don't seem to come. And Cardiac Rehab is doing what to address this?? I also noted that in the Diabetes Education program that Aboriginal people do not come, either. This inequity needs to be addressed, especially with the numbers of aboriginal people with diabetes and heart disease."*
"I think there is good communication between doctors in this community (remote northern area) and the hospital in the city. My doctors in the city provide updates to the doctors here so that I don't have to explain things over and everyone knows what to do."	*"When you have to travel 3 hours to Saskatoon for tests and to see specialists it would be better if these appointments could be organized to cut down on travel expenses and to get quicker results. Most appointments need to be booked 6 weeks in advance. If some of these could be booked close together that would help. When you are sick and in pain 6 weeks is a long time. You start feeling like just a file in someone's desk that no one cares about and you are in pain 24/7."*
"Navigating access for long term care was difficult but with the assistance of our local family practice physician it was made easier."	*"My 89 year old father was placed in a nursing home 40 miles from his home – too far for his wife to visit him. He was put there because there was room – but no consideration was given to the fact that he was not going to have visitors because he was too far away. Initially he was to be put in one 150 miles away, until my sister kicked up a fuss. I know of 5 other people from 4 other health districts who were put in communities where they knew nobody and which were too far away for spouse, friends and family to visit. For instance one French speaking lady was put in a home in which all the elderly residents spoke Ukranian! Because there was room there. In another case, a Cree speaking woman from Cumberland House was put in a nursing home in Hudson Bay! I could go on and on."*

4. Getting Different Results by Doing Things Differently

If we keep running the health care system the way we always have, we can't expect to get different outcomes.

Three years ago the Province was shocked by the tribulations experienced by Baby Paige Hansen. After giving the Saskatchewan health care system three weeks to figure out what was wrong with their baby, the Hansen family finally drove to Edmonton where Paige was diagnosed with leukemia within 24 hours.

The exception that proves the rule? Unfortunately not.

The Baby Paige review found there were systematic issues that needed to be addressed including improved access to care, better co-ordination of care, and more effective communications between care providers and between providers and patients and their families. Three years later, the Patient First Review found a wide variety of similar cases with many of the same causes.

> *"For over a year, my husband went back and forth to our family physician who repeatedly prescribed haemorrhoid treatments for his rectal pain and bleeding. At no time was a fecal sample taken. It finally got to the point where he was in so much pain that I went to the doctor with him. … Finally this doctor called to get my husband into a hospital nearby. Once we got there, we got x-rays right away and serious blockages were discovered. No one really explained to us what this meant. Eventually we went to Regina by ambulance and after a few hours, we were given a diagnosis of rectal cancer. So all that time my husband had been treated for haemorrhoids; he was really suffering from rectal cancer!"*
> *(Patient)*

> *"My youngest daughter, when she was 3 months old, was very ill. I took her to a paediatrician who said she was fine and probably just had a milk allergy but she didn't get any better. I then took her to a walk-in clinic doctor and they told me that she was fine too. Finally I had to take her to the ER because she was getting worse. They had to hook her up to an IV because she was severely dehydrated. They figured out she had a bladder infection that had gone into her blood stream. They told me that she could have died if it had all been left another day. They had to put a catheter in her. None of the doctors before had even taken a simple urine sample. It was a nightmare – it could have been a really fatal error."*
> *(Patient)*

"My mother has been abandoned by our health care system. She had a fractured and dislocated shoulder which was improperly looked after. No follow up x-ray was done at emergency to make sure the shoulder was fixed. One year later three surgeries were required to repair it as a result of negligence by the emergency doctor and poor decision making by the surgeon. She ended up having a severe stroke which has left her mentally incompetent. The system has dumped her in my lap!!"
(Patient)

So what does it take to create a permanent improvement to the system? In our discussion with patients, providers and stakeholders, we identified four underlying conditions for successful transformation:

- **Improved leadership at all levels of health care** – leadership must set the vision, establish the targets, and be vigilant in monitoring the performance of their organizations.

- **Attitudinal/cultural shifts** – changing the attitudes and cultures of health care organizations and staff to think of patients as partners in their own care, and as equal members of the care team.

- **Open communications** – patients want to know who, where, what, when, why, and how the care is being provided. The more patients know (within reason of course), the better they are able to manage their own stress and anxiety levels within the system. Patients, regardless of background or beliefs, must be communicated with in a manner that is appropriate so that they understand their health and next steps.

- **Behavioural shifts** – With the change in attitude/mindset, and more open and culturally appropriate communications, the behaviours of health care staff should shift to be more inclusive with the patient in the provision of care, including them in decision-making, listening to and considering their thoughts and opinions, and treating them as equals.

In the review of other jurisdictions pursuing the goal of a patient-centred system, seven distinct lessons were identified for Saskatchewan. Those seven lessons are consistent with the four from the Patient First consultations and include:

- **Leadership must be fully committed** – in order to shift organizational attitudes and behaviours from current practices to a patient-centred model, the direction must be established from the top, and must permeate through the entire organization. Leadership must be willing to make a long term commitment, and must define what being patient-centred means to their organization. The strategic directions must be reflected in all aspects of the organization including clinical processes, human resource management, education and training programs, corporate communications, as well as performance management.

- **A paradigm shift is required on how patients are viewed** –A shift in thinking needs to happen with organizations and their staff. That shift is going away from the traditional view of the patient as being someone who is visiting a health care professional to be cared for, to a patient-centred view of the patient as an equal partner in the care team. Patients want to feel like they are able to provide input into their own care, that they have options and choices to make, and that they are treated as equal partners ***working with*** a health care team rather then being ***worked on*** by health professionals.

- **The core concepts provided by the Institute for Family-Centred Care encapsulate what it means to be patient-centred** –The Institute's core concepts really resonated with the collective thinking across Canada, US, and the UK on what patient-centred care means. Their four concepts of dignity and respect, information sharing, participation, and collaboration could serve as a set of simple and useful guidelines for any organization looking to become patient-centred.

- **Patient and family participation on committees** –Involving patients and their families is a powerful mechanism for them to provide input into how health care is delivered. In addition to the direct impact on plans and strategies, this seemed to be an effective and meaningful way to instill the values of a patient-centred culture into the organization by showing staff that patient and family input into how health care is delivered is important, and even critical.

- **No system is the same** – there is no "one size fits all" when it comes to health care delivery models, so an organization should be diligent, and start the process of inclusion early in defining the strategy, by taking the time to understand what patients want and expect from them.

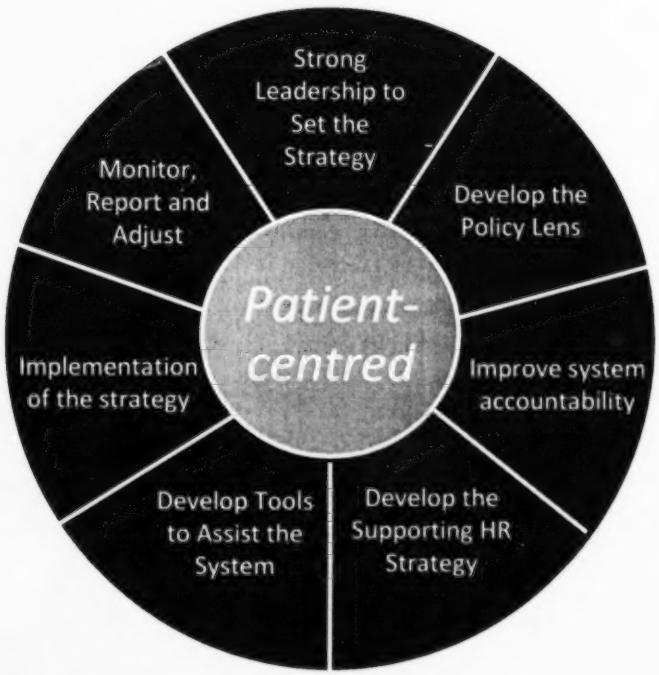
- **Clinical performance benefits can result from being patient-centred** – being patient-centred sounds on the surface to be "touchy feely" and not easily translatable to performance improvement outcomes. The body of evidence is showing that not only are patients' satisfaction ratings going up in patient-centred systems, but organizations are enjoying actual performance benefits (e.g. reduced length of stay).

- **Improvement opportunities are broad and organization-wide** – in order to transform the organization to become patient-centred, changes and improvements are needed in areas that span the entire health care organization. Becoming patient-centred is a journey and it will take each organization many years to make all the necessary changes. This reinforces the point made earlier around leadership making a long term and deliberate commitment to this transformation.

5. Recommendations to Transform the Health System

When we pull together the insights from both the consultations and the jurisdictional review, a clear path emerges for moving forward to a better health care system in Saskatchewan.

Moving to a Patient-centred Health System


Strong Leadership to Set the Strategy
Develop the Policy Lens
Improve system accountability
Develop the Supporting HR Strategy
Develop Tools to Assist the System
Implementation of the strategy
Monitor, Report and Adjust
Patient-centred

The model illustrated above provides a quick overview of the first set of recommendations made to the Commissioner within the detailed report on how the Province of Saskatchewan could approach a system-wide shift to becoming a patient-centred system. This set of recommendations is presented at a high level below, and has been elaborated upon in the detailed report:

1. **Establish strong leadership to set the strategy:** The strategy starts with a commitment from the top. The defining aspect of that commitment is courage. While we believe Saskatchewan currently enjoys a very positive environment to implement change for the better, no matter how collaborative the process, not all stakeholders will support every decision and most decisions will be implemented imperfectly. When mistakes are made or circumstances are more difficult, it will take courage for leaders to stick to the strategy instead of reacting to the crisis of the moment.

2. **Develop a patient-centred policy lens:** The policy lens is fundamental to a long term transformation. The policy lens is a tool that assesses system initiatives from a patient perspective. It asks questions such as, how does the proposed initiative improve the patient experience and how has patient input and feedback been solicited and considered?

3. **Improve system accountability:** The need to improve system accountability was a core finding of all three elements of the consultation process. The input from participants and suggestions for implementation are covered in detail in the report. The key point to make in this summary is "You get what you measure". Since we don't measure the human costs and benefits, we don't incent behaviours that enhance caring and compassion within the patient journey and may, in some cases, unintentionally discourage the behaviour we seek.

4. **Develop the supporting human resources strategy:** Developing the supporting human resources (HR) strategy is a fundamental enabler of a patient-centred system. Saskatchewan has already embarked on the development of a 10 year health human resource strategy. It will be critical to ensure the strategy is aligned with a patient-centred system and not in conflict with it. It is also important to remember that while top-level commitment to a patient-centred system is necessary, it is not sufficient. Patient-centred care is delivered at the front line. With that in mind, it is important that early milestones be developed to demonstrate progress to health providers as well as patients.

5. **Develop tools to assist the system with transformation:** Developing tools is a mechanical but necessary task. Some of these tools – particularly enhancing the Province's existing system of electronic health records – are huge tasks that will take time. Other tools, such as developing provincial resources to assist front-line organizations in process improvement, can be implemented much more quickly and will leverage the advancement of others.

6. **Implementation of the system transformation:** Implementation comes back to the question of where the institutional responsibility will lie. Health system leaders are busy people with many operational and strategic demands on their time. Based on our understanding of successful and less successful Canadian attempts at fundamental health care change, we have recommended that a specific, dedicated Patient First Transformation Team be established to advocate for change and be accountable for the results. The government could establish the team as a program in the Ministry, a program in the Health Quality Council, as a stand alone agency or through another vehicle, just so long as the Patient First initiative has a champion.

7. **Monitor, report and adjust:** Finally, the key point of the "monitor, report and adjust" recommendation is that moving to a patient-centred system is a journey. While we strongly recommend the system leadership develop a continuous set of milestones to focus efforts and provide demonstrations of success, the reality is that fundamental cultural and institutional change requires long lead times during which circumstances change, lessons are learned and adjustment is required.

6. The First Steps

In section 3 we set out the patients' vision for a better health care system. In section 4, we discussed how we move to a better health care system. In this section, we turn to the first steps required to make this vision a reality.

There is no shortage of ideas for how to improve the Saskatchewan health care system. During phases one and two, the patient and provider random discussion groups and work books brought out over 150 ideas on how to improve the health care system. By the end of the stakeholder discussion groups, we had over 450 ideas for improving the health care system. One surprise was the striking level of consensus between patients and providers. Almost all the provider workbooks and discussion participants fully embraced the summary of patient experiences. It some respects this shouldn't have been a surprise given we are all patients whether we work in the health system or not. However, the Patient First Province-wide telephone survey adds further insight as we learned that health care workers are almost twice as likely to be providing voluntary care to a friend or family member as the average. Providers are experiencing the system as patients and fully identify with patient concerns.

All of these ideas have been documented and will be available for health leaders to mine as they develop their own transformation strategies. However, to help establish an overall agenda of change for the better, the responses were coded into an initial set of 19 categories of improvement, with the final set of 6 categories noted below. Full details of this categorization process and results can be found within the detailed report.

This second round of distilling was done to better organize the suggestions to develop a manageable, focused agenda for change for the better. Not surprisingly, the final six categories for improvement are very similar to the five characteristics of a patient-centred health care system as identified in the analysis of positive and negative experiences. Below we summarize the key categories for improvement.

Categories of Improvement

1. **Improving the quality of patient interaction:** This category includes solution areas focused on strengthening patient relationships and communications.
    - Strengthening patient relationship
    - Improving Communication between the System and the Patient

2. **Improving the quality of patient interaction:** This category includes solution areas focused on strengthening patient relationships and communications.
    - Strengthening patient relationship

3. **Improving Communication between the System and the Patient**

4. **Improving system integration**: This category includes solutions aimed at improving coordination of care and health information management.
    - Improving Health Information Management
    - Improving Coordination of Care

5. **Improving access to quality, safer health care**: This category includes issues of improving flow through emergency care, improving throughput of surgeries & diagnostics and reducing the backlog, accelerating and expanding access to mental health care and support, child and maternal care and support, and access for residents in remote and rural locations.
    - Enabling all health care providers to work to their full scope of practice
    - Improving access to hospital care in emergencies and urgent cases
    - Improving Wait times for Surgeries and Diagnostic Tests
    - Improving Home Care Effectiveness
    - Improving Geriatric and Long-term Care Support
    - Improved access for people living in rural and remote parts of the Province
    - Improving Child and Maternal Health Care Support
    - Improving Mental Health Care Support

6. **Improving system accountability:**
    - Improving Performance Management

7. ***Building a stronger health care work force:*** Improving retention and recruitment, staff morale and sensitivity-training
    - Improving health care leadership system-wide
    - Implementing effective strategies to build and develop the workforce
    - Boosting staff morale
    - Improving cultural sensitivity/competency of health care workers

8. **Improving health protection and promotion activity in the Province**: Implementing system-level, community-level and individual-level strategies to promote wellness and prevent illness
    - Improving communication on the role that patients must play in improving and maintaining their health
    - Increase quality of, and access to, health promotion activities and interventions

These categories of improvement have a distinct meaning to the government and health care providers. They will review these categories, and determine what system and/or clinical improvement projects can be implemented in order to address the issues within each category. A summary of KPMG's recommendations to address each category is provided later in this section. But this is the Patient First review, and so the journey to become a patient-centred system must start by ensuring that our analysis of how to improve the system is in the patient's voice, and is easily understandable to patients. "Provider talk" is necessary for the system to implement change; however now we must start thinking like patients in order to plan system change with their needs and voices in mind. The table

below expresses these categories of improvement in the voice of patients and how they have asked for the system to make changes and improvements.

Heard through the patient's voice, these categories for improvement were then used to create a patient-centred prism to provide recommendations to the Commissioner for the government and the health care system on how to implement the improvements needed to address the issues and requests from the patients. These recommendations have been organized by category of improvement and are communicated in system/provider terms of reference so that they are understood by the intended audience, but are always framed in the context of the patient voice. The table below also reflects each of the recommendations made by KPMG to address and improve the issues heard from the patients.

Category of Improvement	Improvements Requested in the Patients' Voice	KPMG Recommendations
• Improving the quality of patient interaction	• Change the way my physician interacts with me, allowing me more time to explain all my concerns and allowing him/her time to explain my full range of options for care. • Provide me with someone I can talk to who is familiar with my care and who can help guide me through the system. • Provide me with information at every stage of my care journey, especially on how long I have to wait and why I have to wait. • Improve your communication with me throughout my care journey, especially letting me know who each provider is and their assigned role.	• Provide incentives / remove disincentives for providers to have longer visit times and engage patients in a discussion about their care options. • Move towards more inter-disciplinary team-based care that leverages physician resources and increases the time available for patients. • Increase access to Case Management / Patient Advocates. • Communicate estimated wait times in Emergency and for surgery shortly after a surgical decision is made, and support patients through their wait. • Provide mandatory staff identification badges that clearly identify who they are and their position in the organization.
• Improving system integration	• Give my doctor tools to communicate more effectively with my specialists and other healthcare providers so I no longer have to repeat my self continuously and my information is not lost between them.	• Build on current information technology infrastructure to expand the use of an Electronic Health Record (EHR). • Expand access to inter-professional care teams. • Develop cross-continuum programs

Category of Improvement	Improvements Requested in the Patients' Voice	KPMG Recommendations
	• As a patient with chronic diseases, improve the way my providers work together to help me reach my health goals. • Improve the coordination of care between my hospital stay and home care.	focused on specific patient populations (e.g. patients with Diabetes) with shared accountability for patient outcomes. • Standardize discharge planning processes.
• Improving access to quality, safer health care	• Reduce the amount of time I have to wait for emergency care. • Reduce the amount of time I have to wait for surgical procedures and diagnostic tests. • Improve/expand the options for care and the ease with which I or my family/caregivers can access geriatric and long term care services in my community. • Make it easier for me to access care when I live in a rural or remote area. • Make it easier for the First Nations and Métis residents to access care, and make it appropriate and sensitive to the needs of my community. • Improve/expand the options for care and the ease with which I or my family/caregivers can access mental health and addictions services.	• Optimize flow of emergency care from a systematic perspective, focusing on the bottlenecks in patient flow concerning the emergency from end to end. • Optimize flow in surgical and diagnostic care from a systematic perspective, focusing on the bottlenecks in patient flow from end to end. Wait times and surgical/diagnostic backlogs are a huge burden to the system. • Develop cross-continuum programs for seniors with complex needs. • Develop a rural care strategy. • Develop a First Nations and Métis health care strategy. • Assess demand for services and develop a strategy to create adequate capacity to meet population need.
• Improving system account-ability	• Teach providers how to meet my needs. • Improve the supervision of staff in the emergency department and hospital wards to prevent rude and inappropriate behaviour. • Pay care providers based on whether my needs are met. • Let me know how my providers	• Implement a Province wide framework to shift the culture of providers towards providing patient-focused care. • Expand nurse manager capacity for improved ward management. • Change performance appraisal systems that reward and recognize patient-centered behaviours, and

Category of Improvement	Improvements Requested in the Patients' Voice	KPMG Recommendations
	are performing. • Give me someone I can talk to when I have a complaint.	alignment with patient-centered values. • Make public reporting on performance mandatory including measures on access, and patient satisfaction in a way that is easily understood by the general public. • Implement a health Ombudsman to field and resolve patient complaints, building on the current model of client representatives and quality of care coordinators already in place.
• Building a stronger health care work force	• Clarify and make full use of every provider's abilities so that I have better access to care and so that providers are better utilized. • Help us to develop more First Nations / Métis heath professionals in the workforce. • Improve working conditions so that my doctor isn't changing every two years.	• Clearly define and make use of providers' full scope of practice. • Develop an advanced practice program. • Develop a First Nation/Métis recruitment strategy. • Provide retention incentives for health care workers to remain in the Province. • Expand nurse manager capacity for improved ward management.
• Improving health protection and promotion activity in the Province	• Provide me with the knowledge and tools I need to help me stay healthy. • Health education is an important part of my community and should be delivered in my community.	▶ Improve public education on chronic disease management and prevention. ▶ Develop strategies to empower patients for self-care. ▶ Involve schools in the promotion of health in communities. ▶ Increase physical activities in schools,

Each recommendation made to the Commissioner is expanded upon within the detailed report. These recommendations were assessed both in terms of the effort required and the potential impact. Recommendations were then further screened to help the system identify both *short term wins* and *longer term priorities*. Within the detailed report, a set of supplementary recommendations were made that represent additional initiatives that could be implemented as supports to the recommendations detailed above.

For details on these supplementary recommendations, please see the detailed report at www.health.gov.sk.ca/patient-first-review.

"Short term" is considered achievable within the first year. The short term initiatives listed in the table below are those that are more easily implemented and with the least amount of effort. The Province should be able to quickly show progress in addressing the patient issues identified. Some of these initiatives include finding ways to communicate more effectively with patients that include providing them with information on their wait time and ensuring they have access to the care they need while they wait. Another early initiative is involving patients in the redesign of care processes. This can be easily achieved and can demonstrate quick results.

"Medium term" is considered achievable within the first three years. The medium term initiatives identified in the table below require more analysis, system change or take more effort to achieve. Examples of medium term initiatives include changing performance appraisal systems to reflect and reward for patient centered behaviours. Another important initiative that will have high impact that can be achieved in the short-to-medium term is the enhancement of nurse manager capacity within the system to provide the important supervisory role and to mentor and provide staff guidance on appropriate patient-centered behaviours. Other initiatives with high impact and medium term achievability include the expansion of Electronic Health Records, and the optimization of Emergency, surgical care and diagnostics.

"Long-term" initiatives will take up to five years. The long term initiatives will take a much longer time to implement and will likely require structure and infrastructure to support their ongoing implementation. These initiatives will also take longer to demonstrate value. One of the initiatives that will have high impact as noted in the table below includes the cultural transformation of the health care system.

The table on the next page outlines the recommended initiatives by both category of improvement and timing. Those recommendations marked with an asterisk (*) are recommendations provided by KPMG that are supportive of and in addition to those provided in the table above. Combined these initiatives will demonstrate immediate action and results while continuing the ongoing transformation of the Saskatchewan health care system.

Recommended Initiatives By Time and Category of Improvement

Implementation Timeline
Short Term (One Year)
Medium Term (3 Years)
Long Term (up to 5 years)
Communicate estimated wait times and support during the wait
Provide mandatory staff identification badges
Celebrate patient-centred performance with recognition & awards*
Standardize discharge planning integrated into the community
Implement a patient ombudsmen
Involve the patient in the redesign of care processes*
Develop First Nations/Métis recruitment strategy
Expand recruitment and retention incentives
Develop a diversity and sensitivity training program*
Improve public education on chronic disease management and prevention
Increase physical activity in schools
Provide incentives / remove disincentives to encourage longer visits
Measure patient-centered behaviours & modify performance appraisal systems
Provide incentives and reward team-based care*
Build on current IT infrastructure to expand the use of EHR
Develop Chronic Care Strategy*
Expand nurse manager capacity
Optimize Flow in the Emergency
Optimize Surgical and Diagnostic Care and increase capacity
Develop Rural Care Strategy
Develop First Nations and Métis health strategy
Survey Patients and Institute formal mechanisms to improve processes*
Develop Management training program*
Increase clinical supervision*
Develop cultural safety perspective*
Develop strategies to empower Patients for self-care
Involve schools and communities in health promotion
Develop health promotion strategy with public reporting on indicators*
Inter-professional team-based care
Increase access to Case Managers / Advocates
Transformational cultural shift
Develop cross-continuum programs focused on specific populations
Develop shared accountability models for patient outcomes*
Expand care paths and clinical guidelines*
Develop cross-continuum program for seniors
Build Mental Health and Addictions capacity
Make public reporting mandatory
Make full use of provider scope of practice
Develop advanced practice program
Expand nursing informatics*
LEGEND:
Improve Quality of Patient Interaction (QPI)
Improve System Accountability (SA)
Improve System Integration (SI)
Build a Stronger Healthcare Workforce (SHCW)
Improve Access to Safer Care (ASC)
Improve Health Protection and Promotion (HPP)

7. Looking Ahead

The Patient First Review is one of a series of initiatives that have been launched by the Saskatchewan Ministry of Health to move the Province's health care system from being provider-centered to becoming patient-centered.

The Ministry and its partners have already embraced the concept of patient-centered care. The need for some improvement is self evident to anyone who has been a patient in the system, and everyone is a patient from time to time, even those who run it. This year's strategic planning process focused squarely on the challenge of doing a better job of meeting patient needs.

However, the Ministry also recognises that those who run the system are often too close to the nuts and bolts to truly see the system as it is experienced. That's where the Patient First Review came into play, giving voice to Patients who have few other inputs into the system as it exists today.

8. Telephone Survey Overview

The final phase of the Patient Experience component of the Patient First Review consisted of a Province-wide telephone survey among Saskatchewan residents. The survey was designed to provide patients with the final word in the review, with questions structured in such a way as to provide quantifiable benchmarks and further check the patient "experience". 1,076 residents had participated in the survey. The respondents consisted of a regionally representative sample of Saskatchewan residents from across the Province: 24% from the North, 19% from Regina, 22% from Saskatoon, 22% from the South and 13% from Central Saskatchewan. The participants were all 18 years of age and older, with a 48%/52% split between male and female respondents. The survey also successfully achieved its quota for First Nations and Métis respondents that are representative of the Province as a whole, representing 8% (82) and 7% (75) of sample respectively.

The detailed results of the survey are provided as an Appendix to the detailed report. Some of the highlights of the survey are provided below. In general, the survey showed that the Province is heading in the right direction but still has a great deal of room for improvement.

The survey benchmarks patient views at three different levels:

Perceptions of the system as a whole.
Evaluations of the overall level of care personally received.
Evaluations of specific patient journeys.

The evaluation of patient journeys is the most distinct aspect of the Patient First Province-wide telephone survey.

The survey also differentiated groups of people who may view the system differently. The survey used three types of segmentations for this purpose: basic demographics including age, gender, First Nations or Métis ancestry and lifecycle status; health characteristics including chronic illness, being a health employee and being a care giver; and general health attitudes. Of the health attitudes, two stood out as particularly critical; consumerism and navigation confidence.

Attitudes turned out to be the most important segmentation variable. Among attitudes, confidence in system navigation is the single most consistently powerful predictor of differences in patient experiences. Almost half of residents - 47% - agree with the statement that "The health care system is so complex that I worry that if I become ill I will not be able to find the help I need." Patients who agree with this statement are much more likely to provide negative ratings of the health care system than those who disagree. In some cases, people concerned about their ability to navigate the system gave negative ratings that were twice as high as those who were confident.

Consumerism as measured by a respondent's interest in doing their own research is also correlated with lower scores. On average those with higher levels of consumerism are about 8 points less satisfied than those who are more deferential. However, the strongest correlation to high system ratings appears to come from confidence in being able to navigate the system. People who are confident they can find the help they need are twice as likely to give the system a positive rating as those who are not confident.

Perceptions of the System as a Whole

Perceptions of the system as a whole are collected both through ratings and belief statements. Three ratings were used:

- "How would you describe the overall quality of health care available in your community today?"
- "In general, would you say that the health care that patients receive in Saskatchewan is better or worse than the health care that patients receive in the rest of Canada?"
- "In general, would you say that the health care that patients receive in Saskatchewan is better or worse than the health care that patients receive in the United States? "

In addition, two agree/disagree belief statements explored overall systems assessments:

- The Saskatchewan health care system puts patients first.
- In general, health care workers in my community care about patients and treat them with respect

The system gets moderate grades for overall quality. Just 12% say the system gives 'excellent' care but even fewer (5%) say it gives 'very poor' care. The common responses were 'good' (38%) and 'acceptable' (31%). In other words, most days the system delivers at least adequate care, but there is room for improvement.

Saskatchewan residents see their system as similar to other systems in Canada but as much better than the American system. One third (34%) say the health care received by patients in Saskatchewan is the same as elsewhere in Canada, 19% say better and just 12% say worse. However a clear majority of 56% say patients in Saskatchewan receive better care than those in the US.

Almost three out of four people in Saskatchewan feel their health care system puts people first (73%) but just 19% strongly agree with that view point suggesting the system is headed in the right direction but still has a way to go before it reaches its destination.

Nine-in-ten (89%) agree that health care workers in their community generally treat patients with respect. With almost half (48%) in strong agreement, this is an area where the system is generally performing well. However, with 41% only somewhat in agreement, there is room to improve even here.

Evaluations of the Overall Level of Care Personally Received

Perceptions of the system as a whole are collected both through ratings and belief statements. Two ratings were used:

- Generally speaking, how would you describe the quality of the health care services provided to you and your family in the last 12 months?
- Generally speaking, how would you describe your ability to access health care services for yourself and your family in the last 12 months?

In addition, four belief statements covered topics related to personal experience:

- I am confident that if I had a medical problem I would receive the treatment I needed in Saskatchewan as soon as I needed it.
- I feel that I have a say in decision-making about my health care.
- My personal health care information seems to get lost in the health care system.
- I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour.

The grades go up when people report on their overall personal experience over the past 12 months compared to assessing the system in general. Generally speaking, the baseline measures for patient assessments of the overall system are 12% of patients feeling it is 'excellent', while 38% feel it is 'good'. When assessing their overall personal experience over the past 12 months, the number saying 'excellent' grows to 19% while 'good' increases to 42%, resulting in an eleven point gain in total good or excellent mentions. Saskatchewan patients feel their own experience is better than average.

Personal access receives almost exactly the same score as overall personal experience, suggesting access is a likely key driver of overall experience.

People under 45 without children are much more favourable on all of these ratings than those with children or those over 45. The groups with the lower ratings are more likely to need the system than those with high scores.

Evaluations of Specific Patient Journeys

Patient journeys were explored through mini-surveys. The mini-surveys included two types of questions:

- **Descriptive** - When did this experience happen and which service silos did you touch?
- **Evaluative** – How would describe your overall experience and your experience on six specific attributes.

In terms of the descriptive results, it is impressive how many of the journeys occurred very recently highlighting the pervasiveness of direct experience with the health care system.

Forty percent of these experiences occurred with the past three months. Seventy percent were within the last year.

The critical role of primary care is re-enforced by the fact that over 80% of these journeys include primary care with the next highest silo experience (diagnostics) trailing a distant second at 53%.

Ratings for the latest experience in the mini-surveys were considerably better than the average rating for the year. Generally speaking, when asked to speak to the overall quality of services provided in the last 12 months, respondents rating their care as 'excellent' or 'good' were 19% and 42% respectively. As it relates the their latest experiences with the health care system, almost 3-in-10 report excellent care and another 35% said 'good'. Just 5% said 'very poor' while 10% said 'poor'. Still room for improvement, but there is much more passionate approval for individual care experiences than for care on average across the year. The most problematic areas included care for an aging friend or family member and care for a mental or emotional health condition. By far the best ratings were for maternal or reproductive care.

Waiting times were the greatest cause for concern in these patient journeys. Just under 3-in-10 patient journeys generated a poor or very poor rating for the length of waiting times. Specialists wait times are the most common wait time issue but wait times for ER are number one for children and elderly care. Primary care and diagnostic waits are also common. Only maternal or reproductive health journeys beat the negative trend.

The other major cause for concern was transitions from one part of the system to another with 20% providing a 'poor' or 'very poor' rating. At 12% 'poor' or 'very poor', the third highest problem (communications of next steps) was directly tied to the transition issue. Transition problems occur primarily when moving from primary care to a specialist or diagnostics. Issues around communication of next steps occur pretty much evenly across primary care, surgery and specialists. Again, maternal or reproductive health journeys fared best on these measures.

Knowledge of staff was a particular problem in mental or emotional health journeys and care for a child with a serious illness. While relatively rare, problems with courtesy and listening skills were experienced very evenly across the system.

Most of the open-ended comments for improvements focus on wait time reductions as a goal or on specific initiatives (hire more staff, increase bed space) to increase capacity in order to reduce wait times. Most of the remaining comments center on improving patient-provider interactions with more time or better communications. Improved communications is particularly important in the case of child and elderly care and, to a somewhat lesser degree, mental or emotional health.

Highlights of First Nations and Métis Results

The Patient First Review included of a number of measures to encourage First Nation and Métis participation such as:

- Dedicated qualitative input sessions for First Nations and Métis participants;
- Quotas to ensure First Nations and Métis were represented in general public qualitative input sessions;
- Invitations to First Nations and Métis providers and stakeholder groups to participate in the provider and stakeholder sessions; and,
- Quotas to ensure First Nations and Métis respondents were appropriately represented in the Patient First Province-wide telephone survey.

Consistent with the findings from the discussion groups, the Patient First Province-wide telephone survey found that First Nations, Métis and residents of rural regions generally report lower satisfaction ratings than other groups. The qualitative input suggests this is the result of two particular challenges. The first is that many First Nations and Métis respondents came from rural and remote communities and shared the access and cost issues experienced by other rural and remote residents. The second problem was a lack of cultural sensitivity and support that was experienced by First Nations and Métis respondents from both rural and urban settings.

Consistent with that qualitative finding, the biggest area of concern from the Patient First Province-wide telephone survey is the finding that 45% of First Nations and Métis participants have experienced unacceptable behaviour compared with 30% among people with other backgrounds.

Looking at the Patient Journey results, First Nations and Métis respondents are fairly typical in their need for acute care. However, First Nations and Métis respondents are more likely to experience every other health condition we measured. The table below provides a summary of the health incidences amongst those First Nation and Métis survey respondents.

Numbers indicate the percentage from each life cycle group to report having had the following system experiences	First Nations	Metis	Neither
Serious Medical Incident	30%	22%	24%
Care for an aging family member	31%	22%	23%
Long-term medical condition that has reduced the amount or kind of physical activity you can do	24%	28%	21%
Chronic illnesses	30%	35%	25%
Mental or emotional health condition	32%	23%	12%
To have a baby or family planning	25%	26%	16%
Care for a dependent child with a serious illness	17%	14%	7%
Addiction	12%	7%	3%

First Nations and Métis respondents' ratings of their patient journey experience are similar to residents with other backgrounds. This is despite the fact they were more likely to experience Emergency Care which is often a driver of poor assessments.

Their satisfaction on the six service attributes was also similar to people from other backgrounds. One exception was somewhat lower than average First Nations satisfaction ratings for listening skills and courteousness, but the differences were relatively small and Métis respondents did not share this concern. This suggests that the high level of experience among First Nations and Métis people with unacceptable behaviour may be more from older experiences than more recent experiences, but more tracking is needed to be confident that there is an improving trend.

9. Research Tracking Recommendations

Historically patient satisfaction surveys conducted within the Province have produced generally positive results and have shown high levels of patient satisfaction with the delivery of care in Saskatchewan. What the Patient First Province-wide telephone survey has demonstrated is while many residents and patients are generally satisfied with the level of care they receive in the Province, there is still a clear demand for improvement.

A summary of the minimum set of measures we recommend be tracked on an ongoing basis and the baseline results from the Patient First Review are provided in the table below:

Summary of Recommended Minimum Set of Measures for Ongoing Tracking

Measure:	*Baseline result:*
• Patients like to do their own research before they take their doctor's advice	• 56% agree
• Patients expect to be major decision-makers in their own care.	• 56% agree
• Patients feel that the health care system is so complex that they worry that if they become ill they will not be able to find the help they need	• 47% agree
• Patient assessment of the overall quality of health care available in their communities today	• 38% describe the care as 'good' while 31% describe it as 'acceptable'
• Saskatchewan residents' view of their health care system compared to other systems in Canada and in America	• 34% say the health care received by patients in Saskatchewan is the same as elsewhere in Canada, 19% say better and just 12% say worse. • 56% say patients in Saskatchewan receive better care than those in the US.
• Patients feel that the Saskatchewan health care system puts people first	• 73% agree, only 19% strongly agree
• Patients who have experienced unacceptable behaviour from health care workers	• 30% have had this experience • 45% of First Nations and Métis have had this experience

Measure:	*Baseline result:*
• Patients believe that health care workers in their community generally treat patients with respect	• 48% strongly agree • 41% somewhat agree
• Patients grading their personal experience over the past 12 months compared to assessing the system in general.	• 19% said their experience was 'excellent' • 42% described their experience as 'good'
• Track specific patient journeys from the patients' perspective by initially asking about conditions rather than service silos.	• Various results depending on journey, see detailed results
• Patients' view of how acceptable the length of wait times are in their journey	• 29% said they were poor or very poor
• Patients' view of how good their transitions are from one part of the system to another during their patient journey	• 20% describe their transitions as poor or very poor. • 53% of problem transitions begin in primary care
• Patient view of how effective/good system communications of next steps in the system are during their specific journeys.	• 12% describe communications as 'poor' or 'very poor'

By initiating and successfully completing the Patient First Review, the Province is making a commitment to patients to look for ways to improve the delivery of care, to make it more patient-centred, and to remain focused on tracking and monitoring patient satisfaction. The recommendations we have made for system transformation and for improvements to the way health care is delivered within the Province will require a long term commitment from the Province and its health care constituents. The recommendations outlined within this section outline how the Province should approach the collection of ongoing patient feedback in order to track and monitor results against the desired goals of becoming more patient-centred and improving patient satisfaction.

1. ***Continue to undertake patient satisfaction surveys.*** We recommend that the Province continue to undertake Patient First surveys such as the one initiated for this review.

2. ***Initiate both broad and focused surveys.*** System-wide surveys such as that undertaken for this review can provide the Province with information spanning the entire system and touching on multiple issues/pain points within the system. We recommend that the Province continue with these system-wide surveys, but also consider initiating mini-surveys that focus on one or more specific issues (e.g. wait times, provider behaviour, etc.). The Province could also follow each process or system improvement project with a survey in order to gather information on the performance improvements that may or may not have been realized from the implementation of different initiatives.

3. ***Continue to survey on several critical items that emerged from the Province-wide telephone survey.*** The detailed survey questions and results provide the Province with a wealth of information to guide and plan system improvements. We strongly recommend that the Ministry and its delivery partners include the following elements in future surveys:

    - **System navigation.** This item had by far the strongest relationship with patient satisfaction.

    - **First Nation and Métis patient experience with negative provider behaviours.** It is important to track both First Nations and Métis ancestry and experiences with unacceptable provider behaviour on an ongoing basis given the high levels of reported historic unacceptable provider behaviour.

4. ***Build on the patient journey approach.*** We would encourage future research to continue to involve individual patient journeys. Not surprisingly, each journey is defined by unique problems and challenges. Solutions that deliver a more patient-centered system need to reflect the unique nature of each journey. It is critical to understand that the patient journey is based on experiencing a condition or symptom. Most patient journeys involve several service silos; as a result a silo based approach fails to capture the whole journey.

    The most important items to test on the patient journey are access and navigation/co-ordination. Communications variables are clearly important, but the relatively high scores on these measures support giving the priority to other areas experiencing more difficulty. The Patient First Review was a first attempt at understanding these journeys. We recommend that the Province continue to analyze and refine these measures and develop additional measures as needed to deal with emergent issues from a patient perspective.

- The first area we recommend as a focus for the development of new measures is the initial diagnoses. As we noted earlier, the Baby Paige experience was not unique. Many of the most powerful patient stories were those relating to delays and failures in diagnoses. Questions related to timeliness and effectiveness of diagnoses would provide an important benchmark to assess how big a problem exists in this area and whether the problems are focused on particular conditions or within particular groups of patients.
- The first priority for refinement is the initial list of patient experiences. Can these items be expressed more simply to make them more accessible to less knowledgeable patients? Are there other important categories that should be added?
- While this survey has served primarily as a descriptive and benchmarking function, it is important that ongoing research be conducted on individual patient journeys to identify key drivers of satisfaction on each journey to ensure that priority is given to the Patient First initiatives that will leverage the greatest improvement in the patient experience. One key to success in the research is to develop larger sub-samples for specific patient journeys.

10. System Recommendations

Similar to reviews, commissions and enquiries that have come before, this Review has developed a wish list of policies and initiatives it believes is necessary. Unlike previous reviews, these are not just the informed views of the Review team. They have been generated by a bottom-up dialogue that began and ended with patients, but also included providers and stakeholders as an integral part of the process.

Many of these ideas have been central and continue to remain central to most health agendas in Canada – waiting list reduction, electronic health records, primary care reform and expanded scope of care to name a few. But some of our recommended ideas have emerged through the unique nature of this review which has challenged us to challenge health care system norms.

First, the most important message from this Review is that the critical success factor in transforming the traditional delivery-based and professionally-based silos of the current health care system to a patient-centred health care system is focusing on process, not just policy. This Review was needed because patients are isolated from their own health care system's planning and governance processes. In fact, patients often feel alienated from the decisions related to their own care. If the process is not changed to give the patient voice an ongoing role, it is inevitable that inertia takes over and the status quo will triumph.

Second, a key benefit of bringing patients into the governance of the system is that we will measure success not just in terms of dollars and clinical outcomes, but in terms of patience experience, both in terms of positive feelings such as peace of mind and comfort as well as negative feelings such as fear, anger and uncertainty.

Third, taking the patient perspective has highlighted the importance of issues of navigation and coordination. While these are often minor items on change agendas generated by system insiders, they are critical drivers of confidence and satisfaction within the patient experience.

Fourth, the core value of a patient-centred transformation is collaboration. Change must be driven from the top, but it is delivered by all levels of the system. A core philosophy of being patient-centred is the engagement of the whole team in a clinical pathway. It is this type of systems-thinking along with process improvement approaches such as Lean that will be critical to achieving the cultural shift that patients are seeking.

Fifth, collaboration includes patients, not only at the planning and governance level but particularly in terms of their own care. The Institute for Family-Centre Care's guidelines do a good job of summarising the conclusions of a wide variety of organizations that have been active in attempting this transformation. As we noted earlier, the patient-centred transformation will not be complete until patients move from being people providers work on, to becoming people providers work with. This is a step beyond the traditional consumer model of customer service to a real working partnership.

Sixth, we have to recognize the system's incentives have often not been designed with the patients' interest in mind. That means that not only are we failing to incent the behaviour we seek, we may well be encouraging the exact behaviours we want to end.

Seventh, while many of the values that are important to the patient experience are intangible, it is critical that we identify measures in order to assess progress. You get what you measure. We recommend the lead agency for the Patient First Review conduct an annual tracking survey based on patient journeys, rather than system silos utilising a consistent set of measures to allow for tracking measures over time.

Eighth, while participants generated a number of ideas that can be implemented at little or no additional costs, there is clearly a need for additional funding to invest in new initiatives to improve the patient experience. Before we ask government for new money, we need to start by reviewing the money already allocated to health care and ask if there is not more than can be done.

Ninth, change will fail without leadership from the top. But how can we call for both a collaborative model AND top-down leadership? By setting clear expectations for leadership. The health system's leadership needs to do three things to create success:

- They need to support and defend the agenda for change which has been driven by patients and their experience. It's the patients' system. It's their right to set the agenda.
- They need to drive decisions. Not make the decisions, that's where collaboration comes in. But they need to identify key decision points and establish processes that enable timely, collaborative decision-making.
- They need to model change. They need to develop tools to enable/facilitate change in the system, and be early adopters of those tools.
- Most importantly, they need to be seen to listen and to respond to the patients' voice.

We know from Ministry's strategic planning process that many initiatives are planned or already underway that have the potential to greatly assist in this transformation and they are highlighted in our detailed findings. But the critical task of changing how we run the system by including patients, changing incentives and measuring results has only just begun.

While the challenge is immense, the team is bullish on the prospects for significant improvement here in Saskatchewan.

It is clear that Saskatchewan is in a unique position to start this journey now.

The fiscal situation is better than any other province in Canada. Of course there is no blank cheque, but there is room not only to sustain but to invest. That opportunity is even greater if the system builds on the Administrative component of the Patient First Review and seeks opportunity to find savings and efficiencies in administrative and support functions.

As helpful as the fiscal situation is, even more important is the openness and enthusiasm of patients, providers and stakeholders for changes aimed at improvement. Participants were keen to participate in our qualitative discussions during all three phases of the consultation. In many groups, particularly with the stakeholders, participants kept talking with each other after the sessions officially ended. But change by itself can raise as many fears as it raises hopes. Change that aims to deliver the vision that patients have for the system is change welcomed by all participants.

The challenge identified in this review is not to change for change sake, but to improve the system so that it more closely aligns with the patient's vision of the promise of Medicare. So long as the focus of the initiative is to keep the best and fix the rest, we believe this enthusiasm can be sustained. The chances of success will be further heightened if the health system's leaders focus on delivering early results both for patients and providers while building the foundation for longer term cultural and structural change.

Patient First

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